

NNLM *All of Us* Community Engagement Network NNLM Reading Club Survey Results

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Introduction

The NNLM *All of Us* Community Engagement Network Reading Club is a selection of "ready to use" book titles with free and downloadable materials. The purpose is to help libraries support their communities' health information needs. Health topics in the books align to the NIH *All of Us* Research Program and the National Health Observances calendar. The kits include eight each: books, bookmarks, discussion guides, NIH Medline Plus Magazines, NIH All of Us Research Program brochures, and reading club book bags. Libraries complete an online application form and acceptance is based on supply, with priority given to public libraries supporting outreach to populations that meet the NIH Underrepresented in Biomedical Research (UBR) criteria. Participating regions are:

- Greater Midwest Region (GMR) Illinois, Indiana, Iowa, Kentucky, Michigan, Minnesota, North Dakota, Ohio, South Dakota, Wisconsin
- Mid-Atlantic Region (MAR) Delaware, New Jersey, New York, Pennsylvania
- Pacific Northwest Region (PNR) Alaska, Idaho, Montana, Oregon, Washington
- Pacific Southwest Region (PSR) Arizona, California, Hawaii, Nevada
- Southeastern Atlantic Region (SEA) Alabama, District of Columbia, Florida, Georgia, Maryland,
 Mississippi, Puerto Rico, South Carolina, Tennessee, Virginia, West Virginia

This report presents responses from the online survey completed by libraries that received the Reading Club Kits.

Method

Reading Club Kit recipients were asked to complete an online survey within six to eight weeks after receipt of their book club kit to provide feedback about their experience with the NNLM Reading Club. The survey instrument was developed by the NNLM National Evaluation Office (NEO) *All of Us* Evaluation Specialist in collaboration with the NNLM Engagement Coordinators. Between November 1, 2018 and April 30, 2019, a total of 261 book club kits were distributed to public libraries. Ninety-four (36%) of the libraries completed the survey between March 16, 2019 and August 6, 2019. Response rates varied across states and regions.

Additional data used for this report are from the spreadsheet used to track Book Club Kit applications and kits distributed.

Results

Results include the data from the book club kit applications combined with the survey results.

Book Club Kits Sent and Surveys Returned

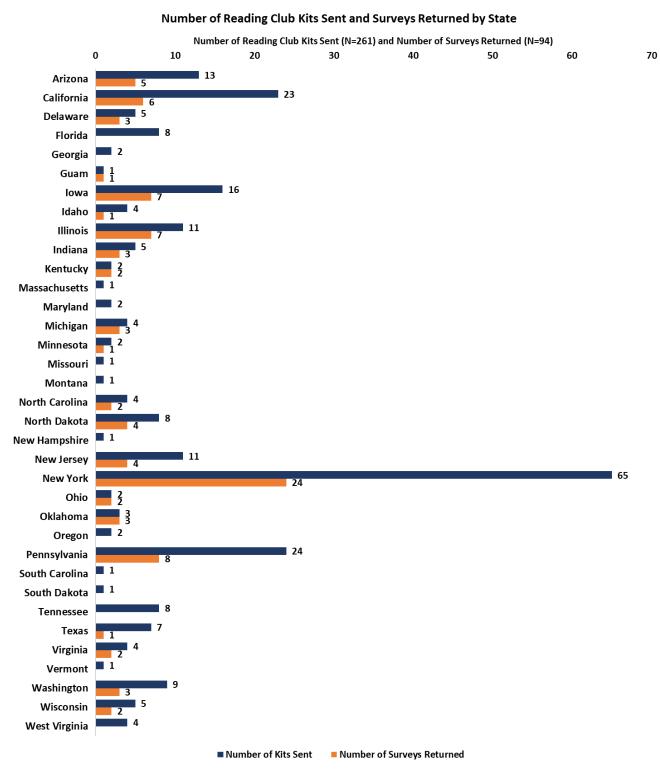


Figure 1. Reading Club Kits Sent and Surveys Returned by State

Reading club kits were sent to libraries in 31 different states and one U.S. territory. Surveys were completed by libraries in 21 different states and one U.S. territory.

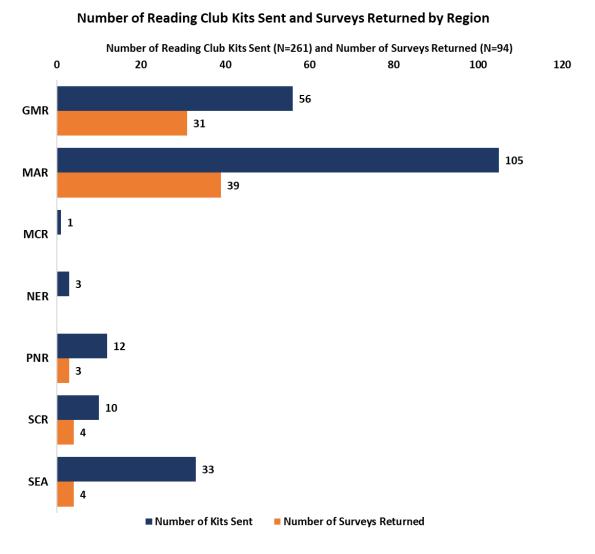


Figure 2. Number of Reading Club Kits Sent and Surveys Returned by Region

Although MCR, SCR, and NER were not listed as participating regions, fourteen of the libraries listed them as their region on the application for the Reading Club kit.

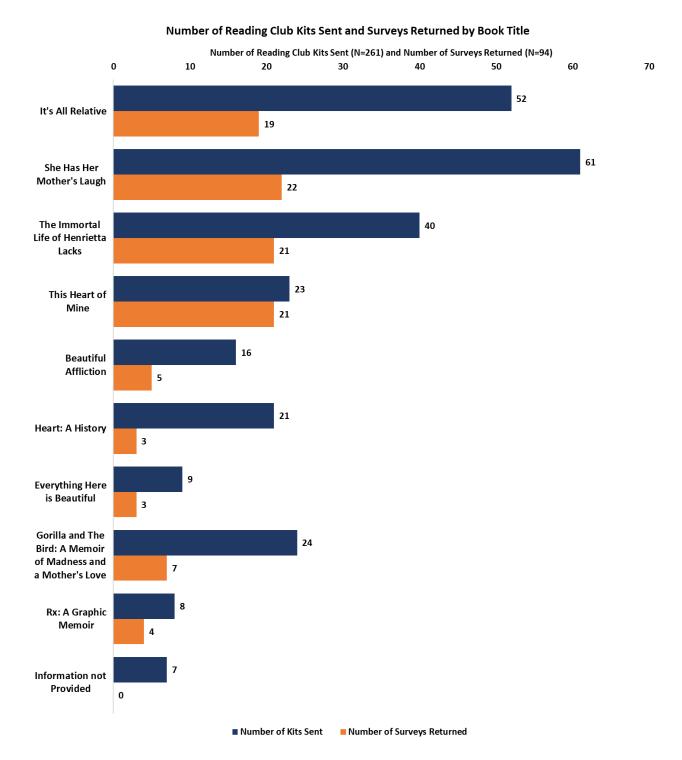


Figure 3. Number of Reading Club Kits Sent and Surveys Returned by Book Title

The largest number of books sent were for the first topic – Family Health History. They *include It's All Relative*, *She Has Her Mother's Laugh*, and *The Immortal Life of Henrietta Lacks*. Likewise, most of the responses received were for these books (66%).

How NNLM Reading Club Kits Were Used

Held a discussion 45 Formed and held a book club 32 With an existing book club Books offered for check out or added to the collection Shared the materials Handed them out to interested persons Incorporated with another program, activity, topic Created a kit for loan to book clubs Set up a display Have not done anything yet Did not respond to the question Held a panel discussion Shared with other groups 0 10 20 30 40 50 **Number of Responses**

How the NNLM Reading Club Kits Were Used

Figure 4. How NNLM Reading Club Kits Were Used

Respondents were asked how the NNLM Reading Club Book Kits were used at their libraries. The most common uses mentioned (and these responses are limited to those mentioned in an open-ended comment) were they held a discussion, formed, and held a book club, used the kit with an existing book club, and offered the books for check out or added them to their collection. Some libraries packaged them into kits to loan out to external book clubs held in their communities.

Underserved in Biomedical Research Populations

Underrepresented in Biomedical Research Populations: Percent of Libraries that Targeted the Population per the Application and Percent of Libraries that Served the Population per the Survey

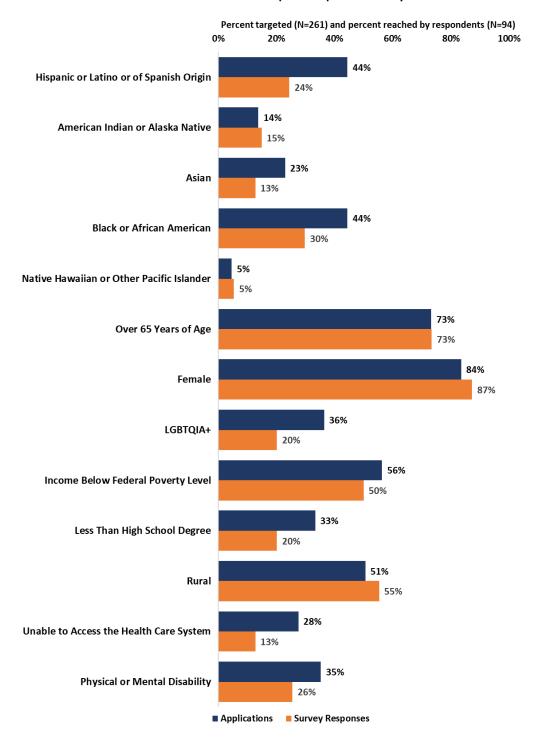


Figure 5. Percent Underrepresented in Biomedical Research (UBR) Populations Kit Applicant Targets and Respondents Actual

Underrepresented in Biomedical Research Populations: The Number of Libraries that Targeted the Population and the Number that Reported they Reached the Population

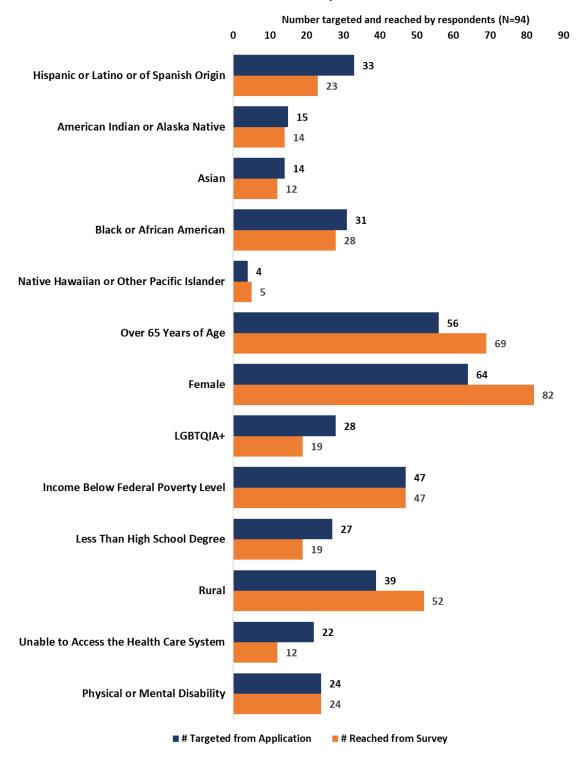


Figure 6. Underrepresented in Biomedical Research Populations: The Number of Libraries that Targeted the Population and the Number that Reported they Reached the Population

When we analyzed all of the data from kit applicants and respondents (unmatched), the kit applicants reported they would target higher percentages of Hispanic or Latino, Asian, Black or African American, LGBTQIA+, Income below federal poverty level, less than high school degree, unable to access the health care system, and physical or mental disability populations compared with the actual UBR populations reported by the survey respondents.

To look more closely, the data in the kit applicants file were matched with the respondents to determine the extent to which respondents were able to reach the populations they reported they planned to target in their applications. In some instances, the number of libraries did not reach the number they had proposed, in others, libraries reached populations they had not proposed. For example, 33 libraries had listed Hispanic or Latino or of Spanish Origin as a target group in their application and 23 libraries reported they had served Hispanic or Latino or of Spanish Origin individuals with the Reading Club Kits. On the other hand, 56 libraries listed Over 65 Years of Age as a target group, and 69 libraries reported they had served Over 65 Years of Age.

NNLM Reading Club Ratings

Respondents were asked to indicate on a five-point scale their level of agreement with four statements. Response categories ranged from Strongly Agree (1) to Strongly Disagree (5) and a lower average score was associated with higher agreement. The average scores indicate that respondents agreed on average that their library patrons were interested in participating in the NNLM Reading Club, and strongly agreed on average that they found the NNLM Reading Club was a helpful offering, they would order the kits in the future, and they would recommend the NNLM Reading Club kits to other libraries.

NNLM Reading Club Ratings

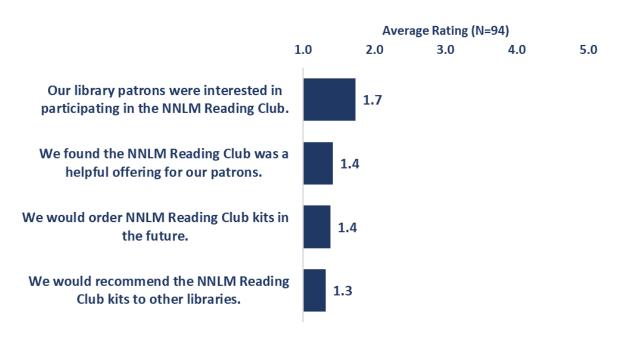


Figure 7. Average Ratings of the NNLM Reading Club

There was some disagreement with each of the statements suggesting that the reading kit did not meet expectations for a small number of libraries. A review of the suggestions to improve the service suggested that among those who disagreed and who commented, the length of the book they had selected was too long.

Table 1. Breakdown of Responses to the NNLM Reading Club Rating Items									
	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	No Response	Mean	Upper Confidence Interval	Lower Confidence Interval
Our library patrons were interested in participating in the NNLM Reading Club	44	33	11	3	1	2	1.74	1.56	1.92
We found the NNLM Reading Club was a helpful offering for our patrons.	61	27	1	2	1	2	1.42	1.27	1.58
We would order NNLM Reading Club kits in the future.	67	19	5	1	1	1	1.39	1.24	1.54
We would recommend the NNLM Reading Club kits to other libraries.	70	18	2	1	1	2	1.32	1.17	1.46

Health Topics of Interest in Respondents' Communities

Health Topics that Libraries Reported Their Patrons Are Interested in Learning About

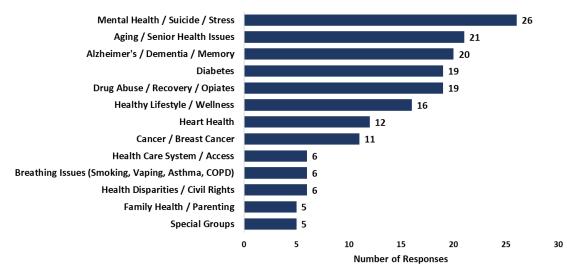


Figure 8. Health Topics of Interest in Respondents' Communities

Eighty three of the 94 respondents answered this question. The figure above shows all the health topics of interest which were named by at least five respondents. Among those who named mental health issues, three specifically expressed interest in mental health among youth. Senior health issues included senior health, aging, and fall prevention. Healthy lifestyles and wellness issues specifically mentioned were nutrition and exercise. Special groups specifically mentioned were Native Americans, women, individuals who speak Farsi, and LGBTQ people.

Other topics (mentioned fewer than five times) were:

- Medicare and health insurance (4);
- Autism and neurological differences (4);
- Neurological disorders such as Parkinson's and ALS, (4);
- Stroke and hypertension (4);
- Genetics and ancestry (4);
- Local health issues such as fracking, lead poisoning, Lyme disease (3);
- Obesity (3);
- Microbiomes (3);
- Vaccines (3);
- Yoga, meditation and mindfulness (3);
- Joint health and joint replacement (2);
- Hospice, palliative, and end of life care (2);
- Sexual abuse and domestic violence (2);
- Rural health care (2);
- Natural or alternative medicine (2);
- Chronic pain (1);
- Health advocacy for self (1);
- Health care information generally (1);
- Sexually transmitted infections (1);
- Health literacy (1);
- Prescribed medications (1);
- Caring for someone with chronic illness (1);
- Lupus (1); and
- Anything (1).

Suggestions for NNLM to Improve the Reading Club Kits

When asked "what could we do to improve this service?" Thirty respondents did not answer the question, and an additional 30 respondents said nothing needed to be done, they were satisfied with the service. Suggestions offered by the remaining 34 were:

- Distributing large print books and materials.
- Provide supplemental health information that relates to the books.
- Add a few more books to the kit . . . 12-14 would be ideal; audio or large print versions.
- Provide more kits.
- Many of the links on the health resources were dead.

- The title we selected was a hardcover > 600 pages, too big to send out as an all in one kit. Keep book selections accessible to the average reader. Populations you're looking to reach may be intimidated by some selections. [She Has Her Mother's Laugh]
- Include more books and program materials.
- Perhaps a bigger selection of books.
- Provide print resources that can be disseminated to the population served.
- More information on depth of books to be read.
- One click ordering or one-stop shop for NNLM supplemental resources so that these materials can be replenished.
- I would love to see more fiction offerings that address health topics, like Lisa Genova. The book was a little dense for our patrons. [She Has Her Mother's Laugh]
- Maybe templates to create signs or bookmarks to advertise the books more. You have all the material organized. I had more trouble getting people started in the book club.
- Offering Reading Club kits in other languages.
- We could use help in promoting/marketing the book club, especially to a low-income community with little access to social media.
- The target audience of the book (teens) doesn't match the target audience for the health literature/resources. They seem to be geared towards an older audience (pictures of older people, etc.) if they want to package these two together, a more conscious effort could have been made to create heart health resources explicitly FOR teens. [This Heart of Mine]
- Please make sure the staff who puts together the questions reads the book so the questions make sense. Question number 7 in "This Heart of Mine." The book did not go into as much detail as the question alluded to.
- The book we received is physically too large for a book kit. It's difficult for patrons to carry the
 entire kit. Typically we select only books 400 pages or less and available in paperback for these
 kits.
- Offer titles more quickly.
- Allow libraries to participate more frequently in the book club kit giveaway.
- Larger quantities of books. This worked in our smaller group, which has 9 people but would not in our larger group, that has 18.
- Keep making resources available. Allowing multiple titles on the same topic would also help.
- I will choose thinner books on a single topic which students can read in a couple of hours. [She Has Her Mother's Laugh]
- There were some great additional materials...maybe have them in a folder or packet so it's easier to distribute?
- I didn't receive an email saying that I was going to receive the reading kits, I just received a large box one day. So it would have been helpful to know in advance.
- Do a book exchange so that we can trade one set in for another.
- I would love to have been able to offer another book selection to continue with NNLM Reading group titles.
- I think the discussion questions could be briefer, but more numerous and varied.
- Expand the program so that more than 8 individuals can participate.

- More books per kit and/or more kits available. Still waiting for a second kit containing a new title.
- If we could return the kit and get another title.
- I think it should be advertised more, so more people know about it.
- An option to receive more copies of the book for larger book groups would be helpful.

Resources Shared

Eighty-three (91%) of the 91 respondents who answered the question reported that they shared the health resources included in the kit with their Book Clubs.

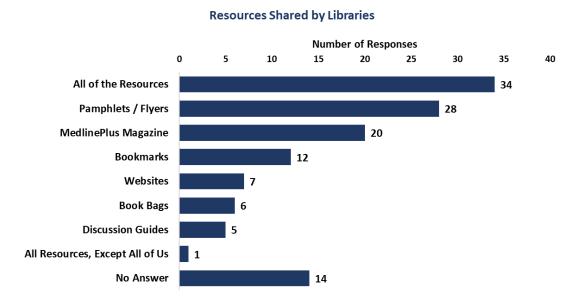


Figure 9. Reading Club Kit Resources Shared by Libraries

One respondent commented that they shared all except the *All of Us* materials due to the sensitive nature regarding Native Americans. Some respondents indicated that they shared specific pamphlets or flyers, such as MedlinePlus (6); *All of Us* (4), Family Health (2), Genetics (2), Heart Health (2), and Mental Health (1).

Reasons provided as to why they did not share the materials were:

- They were only interested in the books. However, I did share resources with the school nurse and the Science department.
- We will be handing out the resources at the book discussion meeting in June.
- Low attendance to group, and the people who attended didn't take the materials.

Usefulness of Health Resources in the Reading Club Kits

Respondents were asked how useful the health resources included in the kits were on a scale from one (not useful) to four (very useful). The average rating of usefulness of the health resources included in the kits was 3.12 (95% Confidence Interval: 2.96, 3.29), which corresponds to a rating of "somewhat useful."

Number of Respondents (N=94) 0 20 40 60 80 Not useful 3 A little useful 14 Somewhat useful 42 Very useful 31

Usefulness of the Health Resources Included in the Kits

Figure 10. Usefulness of Health Resources Included in the Kits

No response

Additional Comments

Additional comments shared by respondents are shared below. Many expressed gratitude for this offering.

- Was interesting to know that many knew about the book had seen it on tv.
- It is good to be connected with health information.
- It's hard to assess how useful the support resources are because the circulating book club kit is still new to the collection. Thank you for the opportunity to share NNLM Reading Club materials with our patrons. Much appreciated!
- Sparked interest in ancestry with the group and they would like to spend 1/2 hr after their book club to now talk about everyone's ancestry!
- We would like to do this again and I think more people might get involved at a different time of the year.
- This is a great program. Please continue it!
- I appreciate your focus on rural communities. Many people who live here are trying to treat themselves with guidance from Dr. Google. Educating them on which resources are reliable was an important part of the information given.

- Non-fiction and medical books especially, tend to be difficult reads in general. If the books are being screened prior to being on the list of offering, perhaps keeping the book under 500 pages and titles which include diagrams of the content discussed.
- NA...except to say Thank You for bringing this opportunity to our attention.
- This book kit was a fantastic resource for our library. The women who attended the discussion
 had such a good time, and they're really hoping that we can do it again. We would love to
 participate in the book club kit program in the future.
- While this attempt was not entirely successful, we will tweak promotions and work with more accessible titles.
- The time we picked for the book club didn't really work for the community. I think we would try the program again on a different day. Also, I think a virtual book discussion would work well. We had a lot of people read the book who didn't show up to the discussion.
- Thank you for the opportunity to participate.
- The Patrons that participated were excited about the book club that our next read will be The Immortal Life of Henrietta Lacks.
- Thank you for initiating this program and for giving us the opportunity to participate!
- Thank you! If it is offered again to libraries, I would certainly be interested.
- We included a note indicating that book club members are welcome to keep the resources provided by NNLM. Thank you very much for this wonderful resource!
- Thank you for letting us participate. Looking forward to the next book discussion kit!
- This is a great service! I would love to see kits geared specifically to Seniors.
- Love the book club program easy to do. You have everything organized, including discussion questions. THANK YOU!
- Staff demonstrated MedlinePlus in Spanish.
- Thank you for this.
- Thank you for this opportunity!
- Glad you offered the service. Book club member was encouraged to research on her own a
 topic that was brought up in the story. Another member said the club was very enjoyable.
 Please keep having these and providing this service to libraries:-) We will gladly help you
 promote:-)
- This was really and exciting project. The response from the faculty and students who participated was very positive.
- Thank you so much for offering this program. We have a lot of interest in continuing a "Health Book Club" at the library. This is huge for us, as the Main Library does not have a large or cohesive community of readers, and so it's wonderful that this program was able to begin to foster and grow one around the topics of health.
- Our patrons really enjoyed the book and were excited to receive the book bag!
- As a result of seeing the materials in the book club kits, I ordered copies of NIH Medline Plus the Magazine!
- People really enjoyed receiving a free book. It led to a good discussion of the issues of the need for donors, what transplant recipients experience and in general, raised awareness of organ donation.

- The book club members love and appreciate the reusable bags. So far, the comments are that the book is funny, an enjoyable and educational read.
- More of a variety with topics that relate to teens.
- Patrons are very concerned with privacy, even after being reassured. This concern was a big hindrance to participation in the discussion.
- Thank you so much for the books!
- Just thank you for letting us be a part of this. The book choices were great and our Book Club had a very good discussion around "Beautiful Affliction."
- Keep things basic and in lay terms. Too many health terms/medical terms can be confusing to the general public.
- I certainly appreciate the encouragement and opportunity to host a book club. It did not happen here at this time. I believe my student patrons are generally swamped with their other competing obligations and struggling to complete their studies. Perhaps a novel on anatomy and physiology would be better accepted. Genetics, the history and development of the field seemed to have too much advance learning and background required to enjoy the book.
- I really enjoy the services that NNLM provides to the community.
- Our readers evaluated our community, wondering how many are afflicted with mental health issues but do not share their stories because it's a taboo subject, because it's unusual, because it's frightening. We had wonderful discussions about how to reach and help folks we know with afflictions, whether their own or within their families.
- Thank you for proving our rural community with this well-prepared Book Club!
- I will use it again for another of our book clubs in the future. I have also offered to share it with other local librarians for their book groups.
- Readers enjoyed reading the book and had a lively discussion. The library plans to share the Kit with other libraries in our consortium.
- This is a wonderful service and participants specifically asked to do more book clubs as a result.
- We all enjoyed this program and we want to participate even further in this program. I
 requested another book from the list and home that we will be approved again and can start it
 in September. Thank you very much for the opportunity. The RX Book was more successful
 than we ever imagined.
- This was an excellent book and will be used in the high school book club this fall, thanks to the sharing of it with the high school librarian.
- Thank you!
- I don't know that anyone had a personal reason, we don't share that much about our own lives in our book group, but they definitely enjoyed the book.
- Thank you for giving our book group an interesting and engaging book, complemented by relevant, useful health information. This was a great program!
- Thank you! Please let us do this again!!!